



# Beyond the visual and verbal: Using participant-produced photographs in research on the surroundings for care at the end-of-life



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## ABSTRACT

The web of relationships between wellbeing and the environments in which people live has long been recognized. However, relatively little research has been conducted about end-of-life surroundings from the perspective of the dying person. In this study, we investigate which aspects of their surroundings are particularly meaningful for the people inhabiting them in the last phases of life, based on participant-produced photographs with follow-up interviews. Twenty-three people were purposefully recruited via specialized in-patient palliative care/hospice units, specialized palliative care home care teams, and residential care facilities for the elderly. Participants were given a digital camera, and asked to take pictures of that which was meaningful for them in their surroundings. The interviewer later viewed the photographs with the participant, asking: “what is this picture of?” and “why is it meaningful to you?” The database consists of 76 photographs with follow-up interviews, which were analyzed qualitatively in an iterative process. These empirical data demonstrate how a sense of being valued, and of being able to maintain contacts with one's daily life and sense of identity appear supported or hindered by features of the care surroundings. These features include a positive aesthetic experience incorporating both sensory stimulation using one's body as well as general ambiance; support appropriate for maintaining a sense of functional independence; and connections with one's past, present and future as a person within a wider world. Corporeality appears crucial for understanding, negotiating and interacting in one's surroundings, while maintaining both physical and social function. This data collection approach was found to offer alternative forms of expression as verbal ability decreases and symptom burden increases, making it useful in end-of-life research and practice development.

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## 1. Introduction and aim

As Rasmussen and Edvardsson (2007) remind us, the webs of relationships between people's physical, psychological, emotional, and existential wellbeing and the environment in which they live

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have long been recognized. Attention has more recently been paid to the surroundings in which people spend the end-of-their-life, as having important implications for “orchestrating” emotions (Worpole, 2009) and “integrating people and place in therapeutic environments” (Glenister, 2012). Parallel to the relief medical technologies and pharmacological treatment aim to provide for physical suffering, we argue that supportive surroundings at the end-of-life (EoL)—whether at home or in an institution—should facilitate well-being for the dying person, his/her significant others, and for staff.

Within a European Union 7th framework-financed project,

OPCARE9 (Mason et al., 2012), Lindqvist et al. (2012) documented staff's self-reported efforts and activities related to creating an aesthetic, safe and pleasing environment in 16 specialized palliative, hospice and home care facilities in nine countries. Attention to sensory stimuli such as qualities of sound, sight, color and textures appeared particularly important in staff efforts in "maintaining connections to the individual's everyday life" (Lindqvist et al., 2012). While the researchers had not expected the extent to which non-pharmacological caregiving activities during the very last days of life would have this focus, nor the variety of activities carried out, their work explored staff self-reports only. Staff may have an idealized view of the value of their efforts, as patients may or may not perceive attempts to make person-based adjustments in caregiving settings, and will interpret both staff efforts and the settings themselves in a variety of ways. Further examination of the literature made it clear that relatively little is known about the experience of EoL surroundings from the perspectives of the dying person and even, as pointed out by e.g. Giesbrecht (2013) those spending time with them, often family members.

Recent literature on EoL care settings has focused strongly on location of EoL care (see e.g. Chen et al., 2016; Cohen et al., 2015; Gage et al., 2015; Gisquet et al., 2015; Hakanson et al., 2015; Kinoshita et al., 2015; Pivodic et al., 2016; Sasao et al., 2015). Another body of literature focuses on the architecture of these settings (see e.g. Worpole, 2009), that is "space" in line with Harrison and Doursih's definition (Hornecker, 2005; Lentini and Decortis, 2010), referring to the physical environment. Our interest in this study is however on qualities and experience of "places" for living at the end-of-life, that is place as involving "... the dimensions of lived experience, interaction and use of a space by its inhabitants" (Lentini and Decortis, 2010). We build further on a body of knowledge at the intersect of human geography (e.g. Andrews and Evans, 2008; Castleden et al., 2010; Evans et al., 2009; Gatrell and Payne, 2014; Giesbrecht, 2013) and empirical research, primarily nursing-based, on experiences of surroundings in the EoL (e.g. Edvardsson et al., 2005; Liaschenko et al., 2011; Moore et al., 2013; Rasmussen and Edvardsson, 2007; Lindqvist and Tishelman, 2015). In the study presented here, we aim to better understand which aspects of their surroundings are particularly meaningful for the people inhabiting them in the last phases of life, using an approach based on participant-produced photographs.

## 2. Methods

### 2.1. Data collection/procedures

We used participant-produced photographs with subsequent interviews to explore perspectives of people in five care settings in the capital city of Sweden and in a university town in the rural north of the country.

Participant-produced photographs are receiving increased attention as a strategy for generating research data with a variety of populations and agendas (Affleck et al., 2013; Balmer et al., 2015a, 2015b; Creighton et al., 2015; Han and Oliffe, 2016; Kantrowitz-Gordon and Vandermause, 2015; Morrison and Thomas, 2015; Oliffe et al., 2008). One reason for this relatively new popularity may be that this approach reaches beyond the constraints of verbal interviewing alone, and can as Sandhu et al. (2013) point out, be particularly effective in exploring issues that may be difficult to speak directly about. It has been utilized in health care research to this end, including studies related to palliative or EoL issues (Campbell, 2011; Campbell and Amin, 2012; Moore et al., 2013). While different terms, e.g. "photo-elicitation" or "photovoice" (e.g. McClymont Peace and Myers, 2012; Olausson et al., 2012, 2013) can be found for similar approaches, there is not always consistency in

how these terms are used; for example "photo-elicitation", the term most common in research contexts, is used to indicate both researcher-generated photographs used to stimulate discussion in interview situations as well as photographs produced by participants. We therefore use the more generic term, participant-produced photographs, for clarity here.

In line with the ethical review board permission for the study (Dnr Ö 29–2012), participants who were judged by staff to be cognitively aware and thus able to provide informed consent were purposefully recruited via staff referral at one specialized in-patient palliative care (PC) facility and two hospices (17 participants), specialized palliative home care teams (4 participants), and residential care facilities for the elderly (3 participants), as shown in Table 1, with 8 participants recruited from northern Sweden and the remainder from the Stockholm region. A total of 24 interviews were conducted with 23 people; one woman participated initially when in an in-patient facility as well as after her return home, enrolled in palliative home care.

It should be noted from the onset that our sampling was not intended to be representative of EoL settings in Sweden. Although Sweden is often reported to have high quality specialized palliative care (World Health Organization and Worldwide Palliative Care Alliance, 2014) and notably low out-of-pocket costs for all health care (Lindqvist and Tishelman, 2016), access remains geographically uneven and predominantly directed to people with cancer (Swedish Palliative Register, 2016). Most deaths still occur in residential home care facilities and acute care hospitals, with access to some form of specialized palliative care (inpatient, home care, or consultancy) at end-of-life varying between approx. 6–23% across the country (Swedish Palliative Register, 2016).

Participants were each lent a digital camera and asked to take three photographs of that which they found important or meaningful to them in their care surroundings. We suggested this number to avoid overburdening participants; however a few participants took and discussed four or five photographs instead. In a follow-up interview at a timepoint agreed upon with participants but generally conducted the next day, the participant and interviewer together looked at and discussed the photographs, after transferring them for viewing on a computer screen. Two questions were used to stimulate discussion: "What is this picture of?" and "Why is it meaningful to you?" with further questions and conversation dependent on the individual and what was told. Each interview was audio-recorded and transcribed verbatim, and along with the 76 photographs produced by the participants, constitutes the database for the analysis.

### 2.2. Data analysis

Data analysis was an inductive, iterative process, carried out in different team constellations. Initially the researchers (authors IG, CT, OLi, BHR) and interviewers (LGS, a RN research assistant and SH, a post-doc acting as both researcher and interviewer), all with backgrounds in nursing, met regularly, to examine the photographs and listen to interviews. This process generated sensitizing concepts of importance for continued interviewing and analysis and steered continued purposeful recruitment to add heterogeneity among participants, region, and type of setting.

More formal data analysis began while data collection was ongoing, through a series of research retreats with the research team. In a reflective process, we first jointly listened to two audio-taped interviews while simultaneously reading the written transcript and viewing the photographs. This stimulated discussion of content and potential salient categories and themes, and methods for continuing analysis. We then made an effort to categorize the photographs alone based on their manifest content as interpreted

**Table 1**  
Background information about participants.

Participant	Age	Sex	Setting	Time between interview and death
1	65	Woman	In-patient hospice	3 months
2	67	Woman	In-patient hospice	8 months 22 days
3	87	Man	Specialized in-patient PC	4 days
4	54	Woman	Specialized in-patient PC	5 months 11 days
5	78	Woman	Specialized in-patient PC	Alive one year post interview
6	57	Woman	Specialized in-patient PC	1 month 7 days
7	67	Woman	Specialized PC Homecare	2 days
8	76	Woman	Specialized PC Homecare	7 months 6 days
9	66	Woman	Specialized PC Homecare	Alive one year post interview
10	63	Man	Specialized in-patient PC	3 days
11	77	Woman	Specialized in-patient PC	1 month 5 days
12	77	Woman	Specialized in-patient PC	5 months 2 days
13	95	Woman	Residential care facility	Alive one year post interview
14	87	Man	Residential care facility	Alive one year post interview
15	86	Woman	Residential care facility	Alive one year post interview
16	54	Woman	In-patient hospice	7 months
17	70	Woman	In-patient hospice	1 month 18 days
18	94	Man	In-patient hospice	4 months 8 days
19	77	Woman	In-patient hospice	21 days
20	67	Woman	In-patient hospice	Unknown, discharged to home
21	87	Man	In-patient hospice	4 months 29 days
22	54	Man	In-patient hospice	3 months 12 days
23	56	Man	In-patient hospice	3 months 22 days

by the researchers. Through listening, reading, and viewing two interviews with photographs deemed to have similar manifest content, it became evident that the descriptions and discussions of the photographs by the participants in interviews shared little similarity with the researchers' initial interpretations, thus clarifying the limits of manifest content analysis of photographs alone and serving to emphasize Kantrowitz-Gordon and Vandermause's (2015) argument that photographs act as metaphors for experience. We continued by focusing on interview text along with each photograph as unit of analysis, with each researcher individually focusing on three-four interviews.

Joint, reflective analysis continued in a second retreat, focusing on relationships found between interview data from each individual photographer and his/her series of pictures. Here, we examined each participant as a case, with three team members summarizing the interview data for one of that participant's three photographs each, and one team member listening to the audio-recorded interview alone. Yet another team member summarized topics that arose in the interview beyond those directly described with reference to a photograph. Based on these complementary summaries, we were able to discuss data related to each participant together. Nine of the 24 interviews were addressed in this manner, and we completed the session by generating a tentative list of substantive categories for coding.

In a last step, framework analysis was conducted by the first and last author together, and subject to discussion thereafter with the full research team. Framework analysis was developed for use in applied qualitative research to heighten usefulness for clinical and social policy application (Ritchie and Lewis, 2003), and has previously been applied by Sandhu et al. (2013) in a study based on participants' photographs. Framework analysis allowed us to use individual photographs as the unit of analysis, while readily maintaining links between photographs and cases in relation to themes.

The summaries of each photograph in the nine interviews jointly examined were first applied to the framework matrix using the substantive categories derived from prior analysis; this was complemented with perusal of each of the remaining photographs/interviews. The initial matrix categories were then synthesized into three inter-related themes, *"The aesthetics of place: Sensory*

*experience and atmosphere"*; *"Negotiating Space—Supporting function, compensating for, and overcompensating for decreased function"*; and *"Connecting Time, Expanding Space"*. The relationship between these overarching themes and the original categories is depicted in Fig. 1.

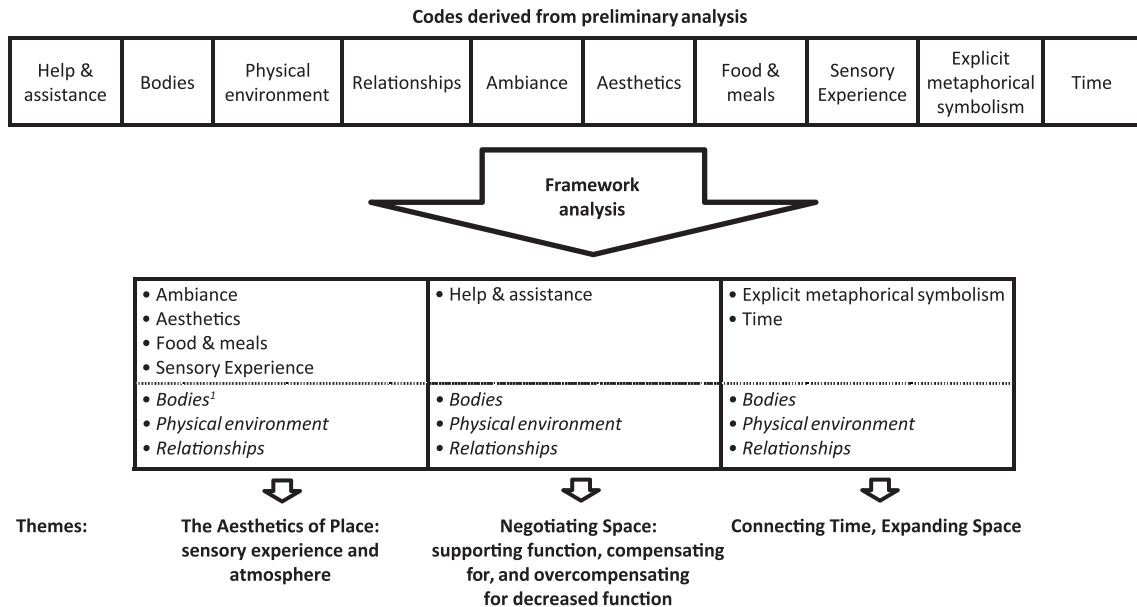
### 3. Findings

As seen in Table 1, seven of the 23 participants were men and the remainder women, ranging in age from 54 to 95, with median age of 70. Ten of the participants died within four months of the interview, with three participants dying within a week. Five people were not deceased after a year; the situation for one person was unknown at that time. Although information on educational level was not systematically collected, the employment background of the participants varied greatly, including professional, white collar, blue collar, and service jobs; detailed information would risk participants being identifiable and has therefore been omitted.

We present our findings below, using a range of photographs to exemplify the three themes when possible. We have not included photographs which depict people or include names of facilities to maintain confidentiality. As noted above, the themes are not mutually exclusive but strongly inter-related; discussion in discrete categories is an effort to tease apart and clarify our findings and interpretations.

#### 3.1. The aesthetics of place: sensory experience and atmosphere

This theme is based on interview text related to aesthetic experience, often focusing on the senses, i.e. sights, sounds, smells, tastes, textures, colors and light. Even issues related to atmosphere or ambiance in the surroundings are included here. Photographs could portray something aesthetically pleasing, but also be used to discuss both a positive and a negative aesthetic in interviews. For example, while pictures of food (see Pictures 1 and 2) generated discussion of the importance of food and the pleasures experienced in taste sensations and social contacts in the dining room, as well as appreciation of the effort staff made to prepare and present meals in an appealing manner, they could also trigger mention of problems with hospital food, of difficulties in eating with others around,



<sup>1</sup> Italicized codes indicate placement in more than one theme.

**Fig. 1.** Process of analysis of components of place, from preliminary codes to themes.



**Picture 1.**



**Picture 2.**

of a sense of pressure from staff to eat or participate in meal situations, and of food and mealtimes as a reminder of bodily changes and limitations.

Many descriptions and pictures related to this theme are said to indicate how patients in EoL facilities felt cared for and prioritized by the presence of beauty around them, with references including the aesthetic value of paintings, furniture, music, light and architecture. There was a recognition of quality, with designers and architects sometimes referred to by name. The ability to have contact with the outdoors while remaining inside or by fluid boundaries between indoor and outdoor environments, through indoor greenery, large windows, and use of light was said to be appreciated (see [Picture 3](#)); some participants even commented on the color and form of assistive devices as part of a positive aesthetic experience. These features, combined with a sense of freedom of choice and general ambiance leading to a sense of calmness and harmony were all described as adding to the positive experience of

surroundings as “informal” and “undemanding”.

In contrast, lack of structure was linked with a negative aesthetic and seen as deeply problematic. [Picture 4](#) is one of the few photographs directly depicting a situation described as negative or problematic, here in an in-patient hospice. This picture was explained by the photographer as showing:

“... a laundry bag that's in the bathroom, which is an unusually large room. And it's filled over the top with laundry and it's probably over a week since it's been emptied ... From the start there wasn't a laundry bag ... for dirty laundry, and then I put it (the dirty laundry) on the floor and it could lay there for a few days and nothing happened and I think maybe after a week, so I think I talked to someone and then I got a garbage bag ... It doesn't seem that anyone ... had the job of checking dirty laundry, because other functions—they come two or three times a day, they come and swab the floor and clean the toilet but otherwise, it feels like they





Picture 3.



Picture 4.

*forgot, that there was a job that no one had responsibility for ... you have different tasks, you check this and you check that... but here no one had gotten that job, it was forgotten ... it's not so fresh-looking ... it's below the standards, you think that someone would have reacted, but ..."*

Although this interview quote may be interpreted as pregnant with symbolism, this participant never made any explicit reference to neglect or to quality of care, keeping the discussion to the

manifest content of the photograph. However, other participants could use more explicit symbolism for negative experiences, for example referring to being bed-bound as a form of "imprisonment" with death offering "*freedom not punishment*."

### 3.2. Negotiating space—supporting function, compensating for, and overcompensating for decreased function

This theme focuses largely on how space is negotiated, closely related to the situation of the participants as both increasingly frail and at risk for losing independence. However, not only physical function was referred to in the photographs and interviews, but social function featured as well. Even intellectual function was discussed and is included in this theme.

In general, a wide variety of assistive devices were photographed. We find, as noted in the description of the previous theme, that assistive devices could be personified—for example, an oxygen concentrator was called Oscar, depicted in [Picture 5](#)— as an indication of the importance of a well-functioning relationship with the device: "*He looks like an Oscar, I think ... and he is secure and calm and he stands there and sighs. It feels good, safe ...*".

On the other hand, important social relationships could be described by several people in terms of functionality—for example this man around 90 years old speaks of his wife, who he has photographed, not only in familial terms, but also in relation to the function she fills:

*"She is a tremendous help ... it's always good to have someone around, a person who can be of help ... Because she's here if something happens and she hears, she wakes up and is always there. You don't have to wait for any help then ... it's the waiting that's difficult, when you lie and wait"*

This description suggests that his wife compensates in part for his lost function and independence. In contrast, when discussing [Picture 6](#), taken by a man who died just days after the interview, the photographer focuses on how his urinary catheter and his hospital bed support his continued ability to function more independently than he would have thought possible:

*"A bed, among the most important things I have, and the catheter, yes. The environment is very important up here ... so that everything around can be manipulated by me as patient ... when you are lying here and can hardly move ... it's very ... I would say*



Picture 5.





Picture 6.

important just because it eases everything you do, like going to the toilet and doing all those things actually ... so it is an incredibly adaptable factor ... without it I don't think I would have managed ... you don't have to think that you have to rush to the toilet the first thing you do, everything just happens automatically ... it's clear that the more you lie here, the more you realize that this is good and that is good, that there are pros and cons ...

... the bed is also a very important part, its' functions and everything. That you can change how you are lying, that you can sit and all that. It means a tremendous amount. Especially ... the ability to move ... I can do a whole lot myself actually and I must say, that means I don't have to turn to the nurses all the time ... I can move myself anyway, favor my own body so to speak. You have to always wait for someone to help you ... It is an incredible difference actually. So that my ability to move is completely different, much more independent, it's amazing, it is. It's a gigantic difference."

This description by a man with death imminent, refers to using available technology to maintain autonomy despite his failing body, sharing similarities with the way Oscar the oxygen concentrator (Picture 5) allowed a sense of freedom in an early phase of sickness for a woman living at home, illustrated in a previous quote.

Other pictures, taken by people in different phases along an illness trajectory, emphasize the aesthetic aspect of physical function. For example a picture of gymnastic equipment is described in positive terms as preserving a sense of health and vitality: "This picture shows equipment that you use for gymnastics or—because you need that other side of your body, the healthy part also wants its share, so to speak ... the healthy part has to compensate for the sick parts" . This perspective is supported further by a middle-aged woman, motivating her choice of photographing an exercise bicycle she never used (Picture 7), to symbolize something of importance to her:

"... I haven't been on one like this, but it can symbolize activity ... because I think it is very important that it is here, that there is activity when you are in a setting like this, so that you don't just end up laying in your room, because that's not good. So ... partly because you physically need to move and build your muscles and so on, because it's good for you. But also because it gives endorphins and you become happy from moving around. And then ... there are other—you can imagine just about anything. It might be making food or reading books together and discussing them if there is



Picture 7.

someone interested in that. Or doing things that stimulate your decreased function, making mosaics (with a laugh)"

As evidenced in the above quote, function was said to be in need of support also in areas other than the physical. Even aspects in the surroundings that supported social relationships were photographed and commented on—from a coffee percolator and other artifacts brought from home to, as described by a middle-aged mother of teenagers, a couch as part of the furnishings in a patient room, shown in Picture 8:

"that sofa, I think it is so fantastic that my relatives or friends can sleep over here if you want, or just hang out. I have two sons and they just lay here, one at each end, and it's so nice. And I think it's so valuable for me that they can be here in a way that is, yeah, relaxed ... that sofa means a lot"

One type of support that is notably missing in these data, and commented on by a few participants directly and others indirectly, relates to a lack of intellectual stimulation. One man photographed the bookshelves in a hospice, criticizing the "crappy magazines", and saying that he had no stimulation to "think new thoughts" as a



Picture 8.

patient there (see [Picture 9](#)). Other participants were less directly critical, but seemed to regard lack of stimulation and boredom as a self-evident part of their day. This seemed sometimes to be exacerbated by friends, family's and even staff's concern about overexertion, safety, fatigue etc—a type of overcompensation related to functions that may not have yet been lost. A discussion about a poster for in-house entertainment at a hospice, led to a many-facetted discussion, including the reliance on watching television as a form of social contact and a mildly-formulated criticism of staff encouragement to eat with others, despite reluctance: *"thankfully, I've been released from it (having to eat with others) for a few days, but that's because I've gotten a new medicine ... that makes me nauseous ..."*.

### 3.3. Connecting time, expanding space

This theme is based on pictures depicting phenomena in the present that are used to generate discussion of the past and the future, as well as offering links with the world beyond the borders of the physical setting. Photograph 10 illustrates this in several ways. This picture is taken by one of the oldest participants, who spent his last months of life in an inpatient hospice facility far from his home. He uses it to illustrate both the picture of the screen as a connection with his home life as well as the computer as a means for communication:

*"I just put in a screen shot from the entrance porch at home ... when I open the computer I see it, and that's the case when we come home also, it's the first thing we see ... even from inside the house ..."*

*... (referring to the what is possible through the computer) you can't lose touch, keep contact with people in a whole different way ... I have a friend who was down in America and she ... sent long letters (via email) every single day ... sending home a lot of pictures ... yup, then I can stay in touch and even with folks at home ... in the village. You just have to connect it (referring to Skype), then they look at it and talk with me, just like you and me, yes, it's a lot of fun ... then I find things out because not everyone writes ... but with what they talk about and write, you know exactly how it is with the lake at home ... Imagine—it's almost like being there yourself ... and it's really good because you remember much better when you look at the picture ... Today I've had a worse day so I don't think I have the energy ... before evening, I usually do it several times a day. Now it doesn't have to be so dull, I never have to be bored ..."*



Picture 9.

This quote succinctly exemplifies many of the issues we categorized in this theme. Numerous pictures of televisions, telephones, and books were used to stimulate discussion of the importance of continued social contact and integration with the world around, both personal social contacts but also a desire to remain anchored in society beyond oneself and one's own circles. These artifacts and others that connect participants with their homes and their memories, sometimes allowing them to maintain habits and preferences from home—for example, the coffee percolator mentioned above—were frequently photographed. Contact with friends and family seem to play a role similar to artifacts from home, that is in maintaining a sense of self, with one's own identity, social roles and history. Some people describe achieving a sense of feeling at home in new surroundings, whereas others explicitly say that this is not the case, sometimes very matter-of-factly. One woman, a patient in a hospice, photographed a sitting area ([Picture 11](#)), and spoke positively about the sitting arrangement, the possibility to sit with others or alone, the spaciousness and how practically and esthetically designed the space was, but concluded by saying *"But for me it's a passageway ... not a room I sit in anyway ... and I don't know why, but for me it's not home ... a home environment, it's not that."*

For some participants maintaining a sense of self may be more important than a sense of home; as one person put it when discussing a photograph of the dining room at an inpatient facility: *"You're not a patient, you are first-of-all a person."* But responses are quite individual—another person at the same facility instead says: *"what happens is that you become a 'non-person'. That's what's so brutal."*

A photograph, mentioned previously, of a poster for in-house entertainment also illustrated key points in this theme. The photograph triggered the participant, an elderly man who died a few months later, to speak not only of its manifest content and the symbolic value it had, but also catalyzed a long discussion with associations to a range of other topics related to the present, the past and the future. He emphasized the importance not only of stimulation and activity, but the music event which was depicted in the poster provided an experience that connected him with his past, even in a physical sense. He had initial difficulty in finding words to express how meaningful it was for him, but said *"it digs up your roots, this jazz music is so programmed in your body so you can't sit still, you feel this rhythm in you the whole time and it's so incredibly wonderful to experience it again"*. He continued to discuss how time



Picture 10.





Picture 11.

was made meaningful and manageable by these weekly-occurring musical events, but at the same time these also provided a marker of his deterioration and thoughts of his limited future, as he noted increasing difficulties in walking to the event week by week: *“it is also an alarm clock when you see how little you are able to do yourself ... it is disheartening in that sense also.”* This photograph also catalyzed comments of the privileged status of being a hospice patient, with invitations to activities that would appeal to someone of his age and background.

#### 4. Discussion

Analysis of the photographs taken and discussed by 23 people living in what is likely to be their last residence in life, and often clearly aware of their approaching death, suggest a variety of ways in which interaction with their surroundings are important in creating what might be considered a general aesthetic of care, including a number of themes. The photographs and following interviews show how a sense of being valued, of being able to maintain contacts with one's daily life, and sense of identity as a person appear to be supported or hindered by features of the place of care. These features include a positive aesthetic experience, incorporating both sensory stimulation, using one's body, and general ambiance; support felt to be appropriate to maintaining a sense of functional independence—not only physically, but also socially and intellectually; and connections with one's past, present and future as a person within a wider world.

Whereas ‘aesthetics of care’ have been discussed from the perspective of care providers, generally in nursing literature, we use the term here to expand upon what Edvardsson et al. (2005) refer to as care “atmosphere”. They delineate five factors related to patients' experiencing the care atmosphere as positive: a sense of it being welcoming; supporting the creation and maintenance of social relationships; staff perceived as willing to serve; feeling safe; and allowing recognition of oneself. These factors all are apparent in the photographs and interviews underlying our analysis. According to these researchers, these five factors were intrinsic in creating an atmosphere they later more succinctly described as incorporating “hospitality”, “safety” and “everydayness” (Rasmussen and Edvardsson, 2007).

While our data appear to support Rasmussen and Edvardsson's prior work, we also note several features that appear to complement their tentative theory. While the body itself is rarely depicted in these pictures, these data further support Watts (2010) in

illuminating ways in which corporeality appears crucial for understanding and being able to negotiate and interact in space and place, in terms of maintaining both physical and social function. For example, a wide variety of assistive, adaptive and rehabilitative care technologies are present in these photographs of meaningful aspects of EoL environments (in 30 photographs by 19 people; included in Pictures 5, 6 and 10) and discussions about these technologies were many-faceted. Technologies depicted in pictures ranged from telephones and computers (Picture 10) to devices like walkers, wheelchairs, hospital beds (Picture 6) and bed lifts, transfer bars, and trapeze bars to oxygen tanks and concentrators (Picture 5). Other tools we noted included alarm buttons, aids for dressing and transfer, bottles with disinfection fluids, vomit receptacle, seat cushions, arm-supports on toilets, etc. In some cases, people were also described in functional terms—as forms of living ‘assistive technologies’, and, one participant explicitly commented a lack of intellectual stimulation and creativity in his surroundings. Analysis of the interview data further indicated the importance of assistive technologies and objects in creating a “sense of place” (Lentini and Decortis, 2010). We were generally struck by the extent to which objects in photographs from inpatient settings could nearly always be described in terms of their function, in addition to the meaning they had for the person depicting them.

Westerlund, a designer, discusses the role of objects (referring specifically to artifacts), and how through interaction with the user, they can become “props”, distinguishable from the background scenery, and with inherent symbolic meaning (2009; pp 44–48). Findings from interviews with family members who witnessed the death of someone close to them, (Kjellgren et al., submitted for publication) as well as with trained caregivers in EoL care (Tofle, 2009) build further on this by highlighting the multiple and dynamic roles that objects play in meaning-making and in maintaining one's identity along a dying trajectory. In this context, assistive technologies and devices seem to be important for both meaning-making and identity in these data. Greenhalgh et al. (2013) point out how older people's subjective and experiential management of their health conditions involved complex interactions, appropriations and adaptations of assistive technologies, as they make use of their unique expertise about their own bodies and capabilities and what works for them. In our study, both the personification of assistive devices and their descriptions through words usually reserved for aesthetic beauty exemplify the crucial role of the functional, such that self-determination and minimal dependency on professionals may act as aesthetic values in themselves.

This postulate may be further supported by the manner in which objects and props were also depicted and described to exemplify a sense of being valued, despite physical deterioration and limited abilities to participate in other areas of life in the same manner as previously (see also Kjellgren et al., submitted for publication). However, as researchers we were also struck by the ‘footprints’ that staff perhaps inadvertently left around patients and which were visible in the pictures, even though they appeared to be rarely intentionally depicted nor spoken of in interviews, which tended to focus more on the positive than the negative. The negative aesthetic in Picture 4 was replicated to lesser degrees in the professional litter often left in patient surroundings—used gloves, wrappings from injections, dressing changes, used hygiene articles, and other remnants of a professional presence. If regard for aesthetics is interpreted as a sign of being valued, lack of attention to such detail might well be seen as a sign of disregard (see also Kjellgren et al., submitted for publication; Edvardsson et al., 2006). Such disregard can be seen as reinforcing an institutional environment in which patients/residents lack control over their surroundings and can be seen as a silent counterpoint to the active



professionally-driven palliative care discourse on “homelikeness” in EoL settings.

There are a number of features in using participant-produced photographs with follow-up interviews that differ markedly from other form of data collection we have used, particularly in EoL research. Participants have had differing ways of dealing with the camera and with photographing—from being very intentional in what is depicted, to seeming to discover their surroundings by taking photographs, with levels of abstraction and symbolism varying greatly. Whereas many types of interview situations related to EoL issues seem to have demographic biases, often appealing to women more than men and to those most verbally proficient (Affleck et al., 2013; Creighton et al., 2015), we found participant-produced photographs to have a broader attraction, with few of those asked to participate being unwilling. While this may reflect staff restrictiveness in referring participants, taking photographs—“doing”, as opposed to “only” talking—seemed to offer a constructive challenge and form of creativity, even for those who did not necessarily define themselves as creative, in situations generally otherwise characterized by loss of activities and functions, as noted by several participants. In this sense, participation in the data collection itself thereby perhaps supported a sense of meaningfulness. Kantrowitz-Gordon and Vandermouse (2015) among others suggest the importance of time for reflection between the taking of the photograph and the interview; given the limited life span of many of the participants in this study, there was instead a short-time lapse to facilitate participation. We have not noted that this has hindered reflection, but is important to remember when considering what these data represent.

In general, we found participant-produced photographs to be readily usable in EoL settings, as this approach is less reliant on cognitive function than many other forms of data collection and could be adapted to offer an alternative form of expression as verbal ability decreased and symptom burden and fatigue increased, as evidenced by people participating just days before they died. However, some limits in these data should be recognized when considering their implications. As noted above, the care settings included in this study may well have a positive bias, in that many of the participants were recruited from specialized palliative care, and acute care hospitals were outside the scope of our ethical review board permission. The heterogeneous nature of the sample and the cross-sectional data prohibits addressing situation-specific features, or drawing correlational conclusions related to a particular situation, a particular type of care, to amount or experience of care, nor to proximity to or awareness of approaching death. Our data are person—rather than institutionally—focused, which means that general guidelines or features for change can not be directly generated.

We have however found these data relevant not only as a source for generating new knowledge in themselves, but also as part of a larger program of research on space and place in end-of-life care, and they have stimulated ideas about how both the data themselves and the methodological approach might be relevant for practice. In many settings, satisfaction with care is explored through questionnaires—given how readily accessible photographing has become with mobile phones, digital tablets and cameras, photographs may well provide another medial form for clinical feedback about care experiences. These data themselves underscore the extent to which the space and place in care settings play a central role in physical, functional and social wellbeing. The photographs generated here, accompanied by quotes from the interviews have gone on to be used as the basis for films used to trigger joint discussion in workshops held with dying people, their family members and staff about prioritized changes in a unit specialized in EoL care, using an adapted experience-based co-

design process (Bate and Robert, 2006, 2007). Even when used in this manner, the photographs and interview data successfully stimulated general discussion beyond that possible by visual or verbal data alone, encompassing both tangible and intangible aspects of the care surroundings. These data thereby served to catalyze discussion leading to change processes which are presently underway, and thus exemplifying how they might have implications for practice in a variety of ways.

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